

# Home Management and Other Resources

## Overview

Family and good friends can all help you adjust to receiving tube feedings. It is normal to feel tired of receiving tube feedings from time to time. The process affects every family in a different way, but it helps to talk through everyone's feelings and contact a professional who can help if necessary. There are resources in the back of this booklet where you can find information and professionals to help. Below are some common areas to think about when someone is receiving tube feedings in the home.

## Keeping Things Normal

Try to live your life as normally as you can. You or your family member should try to remain as active as possible. Socializing will help you maintain a positive outlook. Parents may feel a need to overprotect or treat a child who has unique physical needs differently, which may cause them to become dependent. Your child is only "different" in the way he or she feels. Your child will be happier if rules stay the same and life carries on much the same as before.

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## DAILY CARE

Look at the feeding tube site daily for leakage, bleeding, or skin problems. The site should be kept clean with soap and water and the skin around the opening dried gently. After the initial insertion of the tube, the opening should be healed around the tubing so that there is little leaking and no need for a dressing. If there is leakage that requires a daily dressing or any



other problems with the skin and healing, report them to the doctor if they do not improve with regular feedings and skin care.

Daily care of the feeding tube includes flushing the feeding tube after each feeding or after medications are given. The flush is used to clear the tubing of formula or medicine. Recommended flushes are 5 mL to 10 mL of water for infants and 15 mL to 30 mL of water for children and adults.

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## BATHING AND DRESSING

- ▶ Until the stoma site has healed, it should be cleaned with soap and water and a dry sterile dressing applied. After the site has healed, you may shower and bathe as normal.
- ▶ Clamp the G-tube before bathing.
- ▶ In low-profile devices, make sure the port covers are securely closed.
- ▶ Avoid overly warm water that can irritate tender skin at the tube site.
- ▶ Use only mild soaps and soft washcloths.
- ▶ Dry completely around the stoma, as any dampness can breed bacteria and develop into an infection.
- ▶ Children may chew the tubing or play with it. If a child is allowed to pull or tug at the tubing, they may be able to pull it out. You can prevent this by:
  - Dressing the child in a one-piece undershirt with the tube tucked inside.
  - Wrapping a piece of tape or rubber band around the tubing and pinning the tape/rubber band to your child's diaper or undershirt.
  - Placing the end of the tubing under the tabs of a disposable diaper.
  - Dressing your child in a tube top or wrapping an elastic bandage around the waist, securing the tubing underneath.

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## ACTIVITY

The health care provider will tell you when you or your family member can resume your normal activities. You will usually be told to avoid lifting for 6 weeks after an open procedure, but there are fewer restrictions after PEG tube placement.

There should be no restrictions for a child with a gastrostomy tube. A young child should be able to crawl and should be able to sleep on his or her stomach. Taking a bath or swimming in a pool is also permitted. Be sure to dry the skin around the tubing or the button after swimming or bathing. If you are unsure of a planned activity, ask your doctor or nurse.

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## SCHOOL AND WORK

Discuss the type of work you do with your doctor and ask how long you will need to be away from your job depending on your procedure. Your child should be able to return to school as normal. Your community team, social worker, or the special-needs coordinator at the school will be able to advise you further about this. The staff at the school can be taught G-tube maintenance for emergency situations and possibly assist with feedings. If you or your child particularly enjoys contact sports, ask the medical team for advice.

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## MEALTIMES

Try to keep family mealtimes as normal as possible for socialization purposes. The family member with a feeding tube should be encouraged to join the rest of the family at mealtime, even if he or she is not eating. During tube feedings and for approximately 30 to 45 minutes after the feeding is completed, you or your family member should remain seated upright or lying on your right side if necessary. A young child may use a pacifier while being fed by a gastrostomy tube to help him or her associate sucking with the full and pleasurable sensations of a normal feeding.

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## VACATION AND TRAVELING

There should be no restrictions for travel; however, if you or your family member has complex needs, discuss travel plans with the doctor and ask him or her to write a letter explaining your medical history. This will help if you need to seek medical advice locally.

When traveling out of town, call your home care company ahead of time to arrange for portable equipment, and keep customer service addresses and phone numbers with you while you are away. You should also carry a letter from your consultant explaining that you are carrying medical equipment because of you or your family member's feeding needs. Contact the airline ahead of time to request any special assistance and to know that security will allow all the supplies you need on board.

Keep your supplies with you in a carry-on bag and remember to take extra supplies in case of loss, breakage, or if you end up staying longer than you planned. Always take a travel kit of emergency supplies with you, including:

- ▶ Extra feeding tube
- ▶ Pump with a rechargeable battery
- ▶ Feeding bag or set
- ▶ Feeding syringe
- ▶ 5 mL to 10 mL syringe
- ▶ Rubber gloves
- ▶ Paper towels
- ▶ Container for tap water
- ▶ C-clamp or rubber band
- ▶ Tape measure
- ▶ Emergency phone numbers



For road trips, check the location of your seat belt to avoid pressure on the tubing and insertion site.

If you are planning a beach holiday, cover the gastrostomy with a large dressing to stop sand from getting into it. Sand can irritate the skin near the stoma site, cause an infection, or damage the device itself.

It is important to stay well hydrated and to flush small amounts of water through the tube whenever possible.

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## EMOTIONS

You or your family member may feel self-conscious or have anxiety about your feeding tube. Talking to other people may help. You can try contacting the support groups listed in the back of this booklet or contact local resources through your health care provider.

Children may become more demanding, clingy, or revert to earlier behavior such as bed-wetting if they have been hospitalized or away from you for a while. Reentry into the family life and acceptance and participation in the care of a child with a feeding tube should help the child settle back into a normal routine.

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## BODY IMAGE

You and the rest of your family may feel that much has changed and that everything has to revolve around the feedings for a while. Keeping to your normal routine as much as possible and maintaining the usual mealtimes, rituals and bedtimes may help. Staying as active as possible and allowing good friends to know what you have experienced will help you gain acceptance of this change. There are support groups, references, and websites at the back of this book that will offer the advice of others who are willing to share their experience and answers to some of the questions you and your family may have.

